
How to Start a Brain Injury Support Group



A simple guide to starting a local brain injury support group.

Project STAR at



Charlotte Institute of Rehabilitation
Carolinas HealthCare System

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Project STAR
Charlotte Institute of Rehabilitation
1100 Blythe Boulevard
Charlotte, NC 28203
704-355-1502

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What is a support group? Do I need one?

A support group offers the opportunity to share information and to support one another in an environment of empathy and understanding. It is often from others in like situations that the best solutions to problems can be found. Difficulties and emotions can be discussed freely without judgment, and new friendships can be forged.

Often after an illness or injury, getting on with life is not so simple as one would imagine, especially if that injury or illness leaves the individual with life-long impairments. This is especially true with brain injury. Both the individual and the family often struggle to adjust to the life changes that result from the brain injury. Getting information and services can often be a maze of confusing and conflicting situations, which can lead to frustration.

It is not uncommon for friends to disengage and for extended family to become less involved in day-to-day activities. The family and the individual with the injury can become more and more isolated. As social contacts dwindle, so does the opportunity to interact with others, and



there are few outlets for dealing with the emotional aspects of lifestyle changes created by the illness or injury. Questions often remain unanswered, and the feeling of being alone in the situation intensifies. If this describes you and/or your family, you may benefit from a support group.

Individuals often want education or would like to educate others about brain injury. Support group members can work together to educate the community on brain injury issues.

I need support: how do I find a support group?

In some areas there are established brain injury support groups, but small towns and rural areas are frequently less likely to have a local group. It may be necessary to look in the nearest city to locate the group closest to where you live. Local groups often meet at hospitals, churches or other public facilities, and in some cases in private homes.

Information on existing brain injury support groups in your area can be obtained from the Brain Injury Association in your state. In North Carolina, the location of support groups and the name and contact information for the group facilitator, as well as meeting times and locations, is available at www.bianc.net, or by calling 1-800-377-1464. If a support group is available, you should talk to the contact person to obtain additional information. To locate the

Brain Injury Association in your state visit the Brain Injury Association of America's Web site at BIAUSA.org or call 1-800-444-6443.

If a support group is available, it is important to realize that members' schedules and attendance may vary. It is wise to attend a support group several times to determine its usefulness to you. If there is more than one support group available, it is recommended that you attend each in order to determine the best fit for your needs.

What do I do if there is no support group available?

There are many support groups that exist today because survivors and family members saw the need in their own community and became instrumental in forming one. Initially this may seem an overwhelming task. Starting a support group does require effort and determination, but it can be a very rewarding experience that will benefit all who participate in the forming of a local group. There is no set formula for establishing a successful group, because each community differs in many ways, and these differences can greatly affect the steps necessary to form a group.

Does our community need a support group? If so, how do I start one?

The first step in forming a support group is to determine the need. A need is present when two or more persons would benefit from sharing information and empathy. Almost everyone knows or knows of someone who has sustained a brain injury. Ask friends and relatives if they know of persons who may be interested. People in need of support may travel relatively long distances to participate in a group, so do not limit your exploration to just your own neighborhood.

Once you have compiled a list of people who may be interested in the support group, contact the persons you have learned about or ask that they contact you. Some of those you contact may express an interest in helping get the group started. If even one other person expresses interest, you have established that there is a need.

With the need established, and the first few participants lined up, you are well on your way to becoming an active support group. It is time to start putting the elements in place to make it a reality. Encourage those who are willing to help and share the responsibility. At this point you may want to schedule a planning meeting to determine what steps need to be taken and who will assume responsibility for each step, such as locating a meeting space, refreshment donations and determining a meeting day and time.

It is important to remember that support groups vary greatly from one to another. Each group will form its own unique characteristics as it takes shape, so encourage others to offer ideas and perspectives.

Finding a location for the support group meetings: Where do we look?

Finding a location for the group to meet is the next step in forming the support group. While it is impossible to estimate what participation level your group will reach, it is best to assume that it will grow. Finding a location that will accommodate growth is important. It is usually not difficult to find a facility or organization that will offer free meeting space. Some will even provide refreshments.

Many hospitals welcome the opportunity to participate in programs that benefit the communities they serve. Wheelchair accessibility and being easy to locate are also important factors to consider. Hospitals are easily identified in the community, which makes them good meeting locations if they are willing to provide space. Other options include local churches or civic organizations that may have a meeting room that could accommodate the support group meetings.



After identifying several possible meeting sites, you will need to contact those facilities to determine the best person within the organization to talk to about facility use. Request a meeting to discuss the possibility of allowing your group to meet at their facility. Do not jump at the first offer of space unless it totally meets your needs, and do not get discouraged if some of the facilities you contact are uninterested.

We need to publicize: How do we let people know about the support group?

One of the most important steps in the process of starting a group is to identify ways to get the information to those who may be interested. Following are some suggestions to help advertise your support group.

- Contact the media. This should include not only your town or county, but those surrounding it as well. Media can include newspapers, radio, television and in some cases tabloid-type publications. Contact each media source, give them the information about the support group and request that it is included with their public service or community events announcements. If possible, try to get a feature article about the start-up of the group. A good way to do this is by contacting the person in charge of health reporting and scheduling a time when you can meet with them to share information on your plans. Include facts about brain injury so the

media will understand the importance of this group. Be sure that each reference to the group contains the correct contact information as well as meeting locations and dates if that has been determined.



- Notify professionals in your area of your intent to start a support group. Professionals can include physicians, therapists, nursing agencies and health and human service providers and organizations. You can contact these professionals by writing a letter and stating the intent to establish the support group, the purpose of the group and the location of the meetings, if that has been determined. Ask that they refer any patients who may benefit from the group. Again, be sure to include complete contact information.
- Notify churches or civic organizations to request that the information be included in their newsletter or bulletin. Again be sure to include complete details and contact information.
- Contact your state Brain Injury Association to notify them of your plans to form the new brain injury support group and ask them to provide information about the group to contacts in the local area. If they have a publication, you can request that the support group information be included in the next edition and that your information be filed for referral purposes as well as placed on their Web site.
- Do not be disappointed if you hear from only a few individuals initially. As long as you and one or two family members or survivors are interested, you have the basis for building a support group. Many of the existing groups began with three or less participants and have grown to large groups.
- Organization is important at this stage. Create a list from all of the contacts you receive so that when the first meeting is scheduled you will be able to contact those who expressed interest.
- Start a mailing and phone contact list that you can add to as you receive calls from those who are interested. Refer to page 5 for an example of a contact log. Information needs to be organized and stored together in one location so that it is readily available when you need to add to the listings. Using a notebook is recommended to organize the information and make it readily accessible.
- When you are contacted by a person who is interested in the group you should ask questions that will help you understand any specific needs of the caller, such as what meeting times would be best, special interest information and whether they would be able to help organize the group. Make sure that the contact information is complete so that you can contact them.

Support group contact log

Name: _____	Home phone: _____
Address: _____	Cellphone: _____
City/State: _____ Zip: _____	Preferred meeting schedule:
Email: _____	Day: _____ Time: _____
I would like to help organize the group: <input type="checkbox"/> Yes <input type="checkbox"/> No	Interest: <input type="checkbox"/> Family member <input type="checkbox"/> Survivor <input type="checkbox"/> Professional
Other information: _____ _____	Special interest: _____

Name: _____	Home phone: _____
Address: _____	Cellphone: _____
City/State: _____ Zip: _____	Preferred meeting schedule:
Email: _____	Day: _____ Time: _____
I would like to help organize the group: <input type="checkbox"/> Yes <input type="checkbox"/> No	Interest: <input type="checkbox"/> Family member <input type="checkbox"/> Survivor <input type="checkbox"/> Professional
Other information: _____ _____	Special interest: _____

Name: _____	Home phone: _____
Address: _____	Cellphone: _____
City/State: _____ Zip: _____	Preferred meeting schedule:
Email: _____	Day: _____ Time: _____
I would like to help organize the group: <input type="checkbox"/> Yes <input type="checkbox"/> No	Interest: <input type="checkbox"/> Family member <input type="checkbox"/> Survivor <input type="checkbox"/> Professional
Other information: _____ _____	Special interest: _____

Planning and scheduling the first meeting: How do I contact people?

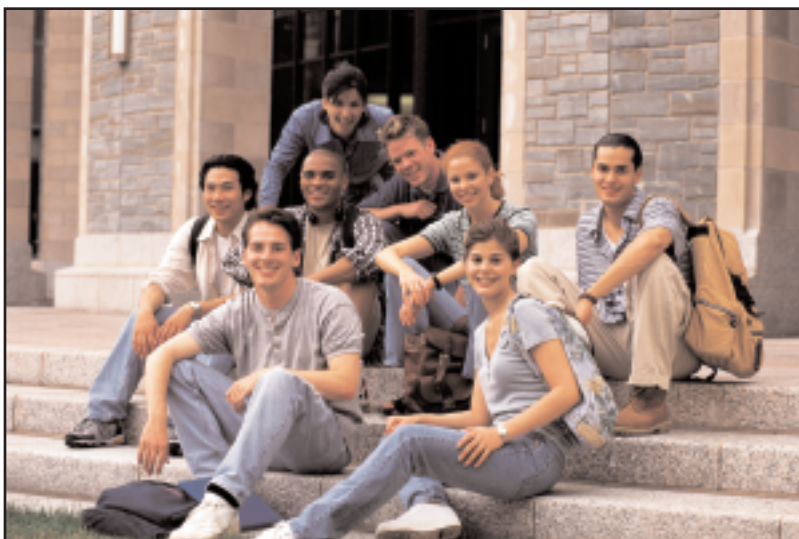
After you have made all of the initial contacts, found a location for your meeting and created a mailing list of those who expressed interest, you are ready to schedule the first meeting of the support group.

Contact the facility where the meeting will be held and schedule a mutually agreeable date and time for the meeting. It would be best to choose a time when most of the individuals who expressed interest could attend.

Try to avoid times where traffic and other issues could keep people from attending.

Once there is an established date and time for the meeting, you must notify those who have expressed interest in attending. Contact those individuals who have expressed interest by sending a notice to those on the mailing list you have developed.

The notice should include meeting time, meeting location and address and a contact name and phone number. If a speaker is scheduled, the speaker's name and the topic to be addressed should also be included. This may be followed up by a phone call to encourage participation.



Contact the local news media and request that the meeting information be included in their community calendar or upcoming events listing. Most local newspapers, radio stations, TV stations and cable companies offer this as a public service with no charge. Also contact local churches, healthcare providers and civic organizations and give them the meeting information. Refer to page 7 for a meeting preparation checklist.

The first meeting is scheduled: How should it be conducted?

The first meeting should be an informational meeting that allows for introductions of the individuals who attend and explores the needs of the participants. Keep in mind that a support group will be defined by the dynamics of the individual members.

As the organizer or facilitator, you will need to take notes and listen carefully to the ideas and issues discussed by others. This will help you steer future meetings toward fulfilling those needs. Allow the group to develop naturally so that it will meet the needs of the participants.

Meeting preparation checklist

Meeting location: _____

Date: _____ Time: _____

- ☐ Media notified
- ☐ Reminder cards mailed
- ☐ Phone contacts made
- ☐ Refreshments arranged
- ☐ Speaker confirmed (if applicable)
Name: _____ Phone: _____
- ☐ Meeting materials prepared:
 - ☐ Name tags ☐ Note cards
 - ☐ Pens ☐ Paper
 - ☐ Handouts and other program materials

Notes:

As the group develops, encourage ownership of the group by the members by assigning them responsibilities.

As the primary organizer, be prepared to lead and facilitate the meeting. The following tips are helpful when organizing the group.

- It is important to arrive early and have refreshments set out and seating arranged. If possible, arrange seating in a circle or around a table to encourage interaction. Having these chores out of the way will allow you to be free to greet people as they arrive. Refer to page 10 for a sample sign in sheet.
- As people arrive ask them to sign the sign-in sheet and point out the refreshments. Encourage them to serve themselves and to make themselves comfortable. Introduce persons visiting for the first time to those group members. This will encourage conversation.
- Name tags should be used so that you will be able to address each person by name when talking to them or making introductions. They also encourage group members to become acquainted and create a sense of belonging, which is essential in a support group.
- Have any handouts or materials prepared in advance of the meeting. They can be placed on each seat in advance so early arrivals can review them. It is important to remember that you are drawing together strangers and that each person has a different comfort zone. Some will socialize immediately while others will sit quietly and look through any available materials. Allow at least 10 to 15 minutes for people to arrive and socialize if they wish.
- Open the meeting by introducing yourself to the group and giving a brief personal overview. It is appropriate, and necessary, that you share openly and honestly whatever life situations that have led you to start the group. This may serve as an icebreaker and make those in the group more comfortable in sharing their own stories. It is important that group participants feel comfortable sharing their information with each other. Ask that the information shared within the group be treated as private and confidential. Some individuals will feel more comfortable sharing information if they understand it will not be discussed outside the meeting.
- Ask each participant to briefly share his/her story with the group if they wish. Do not pressure those who seem reluctant to share information. Each person must be allowed to participate within his/her own comfort zone.
- When preparing the agenda for the meeting, schedule time at the end of the meeting for the group to socialize. This will give individuals an opportunity to discuss individual issues with the speaker and the other group members.
- Ten to 15 minutes before the time scheduled for socializing, start bringing the meeting to a close. Thank the group for sharing, give your contact information to each person and make sure everyone has placed their contact information on the sign-in sheet. Give the group the date, time and location for the next meeting (if one has been planned) and remind them that the information on the sign-in sheet will be used to notify people of the next meeting.

- The first meeting may continue after you have closed it. Encourage social interaction and allow people to leave at their own pace. Make yourself available for questions.

- Be prepared for some people to become emotional. This may be the first opportunity some have had to share their experiences after brain injury. Allow time for composure if individuals become emotional and tearful. It is recommended to have tissues available. It is important that each person be given a chance to speak. Allow others to empathize with the emotional participant and then guide the meeting back to the agenda. After the first meeting it is not necessary for each group member to share his/her story.



- After those attending have shared their stories, it is time to start to develop the group goals and to establish what those present hope to gain from attending the group. This can be determined by a combination of a questionnaire and discussion. Many issues are similar, while some of the group may have some unusual and specific needs. It is important to include all issues even if it applies to one person. Inclusion is what makes a support group successful.

- A questionnaire may help start conversation and give the group organizer a clear idea of what types of needs are most prevalent in the group. In addition, it provides information on members interested in taking on a leadership role with the group. Following are examples of a sign-in sheet and a sample questionnaire. The questionnaire can be filled out during the first meeting. An open discussion of the answers can be helpful in identifying common concerns and interest. Refer to page 11 for a sample questionnaire.

We now have a support group: How do we keep it going?

Just as starting a support group takes work and organization, so does keeping it going. Some of the most important things to remember are:

- As long as two people attend, you have a support group.
- Keep the meeting date and time consistent each month.
- It is important to plan meetings well in advance and to notify everyone on the mailing list as well as the local media.
- Encourage group participants to decide on speakers and program content.
- Share responsibility. Ask others to participate in the meetings by providing refreshments and planning other activities.

Brain injury support group sign-in sheet

Date: _____

Name	Address	Contact information
_____	_____	_____/_____
_____	Street	Home phone / Cellphone
_____	_____	_____
	City State Zip	Email address

Name	Address	Contact information
_____	_____	_____/_____
_____	Street	Home phone / Cellphone
_____	_____	_____
	City State Zip	Email address

Name	Address	Contact information
_____	_____	_____/_____
_____	Street	Home phone / Cellphone
_____	_____	_____
	City State Zip	Email address

Name	Address	Contact information
_____	_____	_____/_____
_____	Street	Home phone / Cellphone
_____	_____	_____
	City State Zip	Email address

Name	Address	Contact information
_____	_____	_____/_____
_____	Street	Home phone / Cellphone
_____	_____	_____
	City State Zip	Email address

Brain injury support group questionnaire

Name: (optional) _____ Phone number: _____

Address: _____ City/State: _____ Zip: _____

- What do you feel are the most frustrating things that you are currently dealing with?

- Do you feel that services for individuals with brain injury are adequate?

☐ Yes ☐ No Please explain why:

- Are you and your family getting the services you need?

☐ Yes ☐ No What services do you need that you have not been able to find?

- What do you hope to gain from participating in a support group?

- What type of speakers or other information would most benefit you?

- Do you feel that the time and location of the meeting is convenient?

☐ Yes ☐ No How often would you like the group to meet?

- Would you be interested in helping lead the group or helping with future meetings and events?

☐ Yes ☐ No If yes, how will you be able to help?

Comments:

The support group needs a sponsor: Where do we look for help?

Even with a small local support group there can be some cost. Postage, the cost of copying handout materials and phone calls can add up over time. Unfortunately, many of the people who attend support groups deal with fixed or limited incomes and are unable to contribute to



these expenses. Finding a sponsor for the group may be the answer, and may be easier than you think. Examples of possible sponsors include hospitals, human service providers, health organizations, civic clubs, etc. Asking for donated services is one way to gain the financial assistance for your support group, as well as asking for cash donations.

The first step in this process is to make a list of the expense items and match each one to a list of businesses and

organizations within your community. Approach each with a written description of your support group and its goals along with a request for the specific items or services that you need. Below are some examples of community supports:

- Churches or businesses, as community outreach, can offer the use of copy machines and can include support group mail-outs in their postage budgets.
- Grocery stores can participate by donating refreshments for meetings.
- Local physicians, medical personnel and community organizations can participate by donating literature that would interest the group.
- Businesses can be asked to assist by sponsoring special outings or sponsoring events that the group can attend.
- Local entertainment, such as theaters, sport teams and other public venues, may be approached for free admission for group members.

Maintaining a treasury may not be necessary in the early stages of forming a group. However, it may be something to look at in the future. Many groups use the natural supports within the community. If the group receives cash donations, keep records and receipts of what the money was used for.

The future of your group

If you have put the basics of this guide into action, you now have a functioning support group within your community. As your efforts reach others, and your group grows, it is important to remember the principal reason for the support group. We will end this book the same as it began, by reminding you of why you formed the group.

A support group offers the opportunity to share information and to support one another in an environment of empathy and understanding. It is often from others in like situations that the best solutions to problems can be found. Difficulties and emotions can be discussed freely without judgment and new friendships can be forged.

For additional information about brain injury, or support groups in your area, contact your state Brain Injury Association.

Brain Injury Association of America

Family Help Line: 1-800-444-6443

www.biausa.org

Brain Injury Association of North Carolina

Family Help Line: 1-800-377-1464

www.bianc.net

Brain Injury Association of North Carolina Family and Community Support Centers:

Triangle Family and Community Support Center

PO Box 748

Raleigh, NC 27601

919-833-9643 or 1-800-377-1464

Family and Community Support Center

At Charlotte Institute of Rehabilitation

1100 Blythe Boulevard

Charlotte, NC 28203

704-355-1502 or 1-877-962-7246

Eastern Family and Community Support Center

202 East Arlington Boulevard, Suite T

Greenville, NC 27834

252-439-1900 or 1-800-697-3115